

Members

Sen. Marvin Riegsecker, Chairperson  
Sen. Rose Antich  
Rep. Sheila Klinker  
Rep. Robert Alderman  
Thomas E. Van Meter  
Sylvia Brantley  
Suda Hopkins  
Joanne Rains  
Betty Williams  
Sally Lowery  
Ervin Picha  
Christopher Durcholz



# INDIANA COMMISSION ON MENTAL RETARDATION AND DEVELOPMENTAL DISABILITIES

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## MEETING MINUTES<sup>1</sup>

**Meeting Date:** September 5, 2001  
**Meeting Time:** 10:00 A.M.  
**Meeting Place:** State House, 200 W. Washington  
St., Room 233  
**Meeting City:** Indianapolis, Indiana  
**Meeting Number:** 2

**Members Present:** Sen. Marvin Riegsecker, Chairperson; Rep. Sheila Klinker; Rep. Robert Alderman; Sylvia Brantley; Suda Hopkins; Ervin Picha; Christopher Durcholz.

**Members Absent:** Sen. Rose Antich; Thomas E. Van Meter; Joanne Rains; Betty Williams; Sally Lowery.

Senator Riegsecker called the meeting to order at approximately 10:20 AM. Upon agreement of the Commission members, Senator Riegsecker commented that the Commission's schedule of meetings will be changed as follows: Meeting #3 will be Thursday September 27, 2001, at 1 PM at Muscatatuck State Developmental Center (MSDC); and Meeting #4 will be Thursday October 4, 2001, at 10 AM at the State House. The topic of discussion for Meeting #3 will be the closure of MSDC. Meeting #4 will address the issues previously scheduled for Meeting #3 (*Olmstead*, Governor's Council on State-Operated Care Facilities, mortality review process, group home issues), as well as

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<sup>1</sup> Exhibits and other materials referenced in these minutes can be inspected and copied in the Legislative Information Center in Room 230 of the State House in Indianapolis, Indiana. Requests for copies may be mailed to the Legislative Information Center, Legislative Services Agency, 200 West Washington Street, Indianapolis, IN 46204-2789. A fee of \$0.15 per page and mailing costs will be charged for copies. These minutes are also available on the Internet at the General Assembly homepage. The URL address of the General Assembly homepage is <http://www.ai.org/legislative/>. No fee is charged for viewing, downloading, or printing minutes from the Internet.

additional discussion of the First Steps program.

**Maureen Greer, Assistant Deputy Director, Bureau of Child Development, Division of Family and Children (DFC), Family and Social Services Administration (FSSA)**

Ms. Greer provided the Commission with a packet of information regarding the Infants and Toddlers with Disabilities program ("First Steps"). (See Exhibit 1). This packet contains a cover sheet and the following documents:

- Document 1: General program overview (legislative authority, lead agency, eligibility, services provided, local infrastructure, provider/personnel capacity, personnel development, finance system, funding).
- Document 2: Update on sliding fee scale and utilization review development and implementation.
- Document 3: General program demographic information.
- Document 4: Number of children in program, by county, race, and income level.
- Document 4A: Example of county profile report.
- Document 5: Number of children served, by provider type.
- Document 6: Number of referrals to system points of entry (SPOEs), by county.
- Document 7A: Referrals not moving to intake, FY 1999.
- Document 7B: Referrals not moving to intake, FY 2000.
- Document 7C: Referrals not moving to intake, FY 2001.
- Document 8: Description and results of outcome measurements used by DFC for First Steps services.
- Document 9: Billing and payment information, by county, for service coordination, speech therapy, and developmental therapy.
- Document 10: Cost of operation for central reimbursement office (CRO).
- Document 11: Total administrative cost of First Steps program, by category of expense.
- Document 12: Information regarding First Steps funding sources.
- Document 13: First Steps program evaluations.
- Document 14: 2000 annual performance report sent to the federal government.

In addition to Exhibit 1, Ms. Greer provided the following information:

- Indiana's First Steps program has the second broadest eligibility criteria in the country.
- Services provided under the First Steps program often help to reduce the need for special education services and supports that First Steps eligible children would otherwise need.
- To date, in 2001, the program has served approximately 17,000 children.
- Indiana's unified training system was the first of its kind in the country.
- The CRO works to make sure that for each child, state funds are used as the source of payment for First Steps services only after all other funding sources available for that child (e.g., Medicaid, TANF) have been utilized.
- The average cost of First Steps services per child for FY 2001 was approximately \$2,800.
- Development of a sliding fee scale is taking place on a time frame that should allow DFC to implement the scale on July 1, 2002, as required by legislation passed in the 2001 session.
- Children in the First Steps program often do not receive services for an entire year. Many children come in and out of the program due to moving, illness, or change in family circumstances.
- The cost per child of First Steps services has remained relatively stable over the years. The increase in the program cost is mainly due to the increased number of

children receiving services.

- The racial demographics of children in First Steps very closely reflect the demographic make-up of the state.
- DFC has placed individuals in both the Lake County and Marion County First Steps offices to focus specifically on outreach to the African American populations of those counties.
- Federal law requires First Steps services to be provided in a child's natural environment, which results in many children receiving a large amount of services in their homes.
- Approximately 23% of children who receive First Steps services go on to special education programs in the schools. The average annual cost of special education for a child is \$13,000 for each year of the child's education.
- DFC is in the process of developing a standardized survey to use in determining why families voluntarily leave the First Steps program.

Responding to questions, Ms. Greer informed the Commission as follows:

- First Steps is able to have an adequate outreach effort in smaller communities through cooperation with many other programs and providers (e.g., Head Start, child care referral groups, Maternal and Child Health programs, WIC clinics, food pantries, grocery stores, laundromats, hospitals, and midwives) who are likely to have contact with the individuals who need First Steps services.
- The proposed sliding fee scale is not based strictly on a family's gross income. Deductions are allowed for certain medical and personal care expenses. Comments received on the proposed scale have been mostly positive, although most respondents would rather not have any cost sharing requirements. Regarding non-payment of a required co-pay, DFC's policy is that no child will be denied services because of a family's failure to pay. Also, because the cost of collections would likely be very great, DFC will not pursue this route but will instead report a family who fails to meet its cost-sharing responsibility to a credit bureau. Providers will not be involved in the co-pay collection process.
- There are many reasons why a child who is referred to First Steps does not enroll in the program. For example, a child may be referred to the program upon failing a hearing test and the family decides to wait and see what happens before accessing services. In such instances, the families are made aware of their options under the First Steps program and told how they can enroll for services at a later time if they should decide to do so. There is a difficult balance that must often be made in these situations between a family's right to privacy and their right to make decisions regarding their child versus being sure that the family is making an informed choice concerning receiving services.
- The services that a First Steps child receives must be approved by a team of individuals involved with the child's care, including the child's medical provider.
- Although the General Assembly passed legislation in 2001 to allow First Steps to access a child's insurance coverage, this is a very complicated issue as federal law does not allow states to access ERISA-based plans and a large percentage of Indiana residents with insurance coverage are covered by ERISA-based plans.

At the request of the Commission, Ms. Greer agreed to provide the Commission with information regarding services by provider type for years prior to FY 2001.

#### **John Dickerson, Executive Director, The ARC of Indiana**

Mr. Dickerson noted that the First Steps program has made great achievements but still has many challenges as evidenced by the many divisive discussions over the program's

future that occurred during the 2001 legislative session. Mr. Dickerson remarked that one of these challenges is to assure accountability of all those participating in the program, both families and providers. He also stated that it is essential to make sure that the program serves all eligible children appropriately and adequately and that there is adequate access to needed services in all parts of the state.

Mr. Dickerson informed the Commission that the ARC is opposed to First Steps families being required to bear any of the cost of services, as this amounts to an additional tax on those families with special needs children. According to Mr. Dickerson, the sole purpose of a cost-sharing requirement is to limit participation, not to save money. Fourteen other states have implemented similar requirements and have spent as much money collecting the co-pays as has been collected. There is a great concern that the current economic condition of the state may jeopardize First Steps and other programs that provide services to individuals with disabilities, so it is very important that the Commission serve as a forum to review these types of programs and make whatever recommendations to the General Assembly that are necessary to protect these vulnerable citizens.

Responding to questions, Mr. Dickerson noted that an FSSA working group has been looking at 18 specific recommendations from a recent independent audit of First Steps. For example, one recommendation is that a child who requires many different, complicated types of services have a master service coordinator (i.e., someone with a great deal of experience with highly complex cases) rather than someone who is less experienced with the system. He also noted that cost sharing may actually increase utilization due to a family's determination to "get what they pay for." Mr. Dickerson also stated that it is very difficult in any case to determine what amount of services is appropriate, but the adoption of best practice guidelines might be a good way for families to have an understanding of the types and amounts of services their children really need so they can make the best choices for their children. As for reports of therapists who have "bullied" service coordinators into adding more services to a child's service plan, Mr. Dickerson noted that any action concerning this issue must be based on data, not merely anecdotal evidence. In addition, Mr. Dickerson remarked that the greatest measure of success for the First Steps program is the number of children who complete the program and do not need to be placed in special education in school.

**Jerry Allen, First Steps Central Reimbursement Office Project Director, Financial Management, FSSA**

Responding to questions, Mr. Allen noted that the largest portion of First Steps expenditures is financed through federal Temporary Assistance to Needy Families (TANF) block grant funds. TANF funds are used to pay for services provided to children who receive monthly TANF assistance or whose family income is less than 250% of the federal poverty level. Only about \$5 million to \$6 million of state funds are used for First Steps each year, and this amount has remained relatively constant over the last several years. There is no federal match for state dollars spent in First Steps.

John Dickerson noted that the future of TANF funds, which are currently legally used to make up shortfalls in the First Steps programs, has yet to be determined by Congress. Additionally, even though these block grant funds are technically federal funds, states have a great deal of latitude in how they are spent, so many legislators actually look at them as state dollars. Also, using TANF funds to make up the First Steps shortfall could pose a problem in the future if the need for traditional welfare assistance increases.

**Suzann Shackleton, licensed social worker, Warren County**

Ms. Shackleton commented on the importance of retaining the local SPOEs and coordinating councils in all counties, even the rural counties. She noted that this local connection is of vital importance in assuring that individuals who need First Steps services are identified, served, and supported.

**Denise Arland, Chairperson, Interagency Coordinating Council (ICC)**

Ms. Arland stated her belief that overutilization and cost-sharing are separate issues. She agreed with Mr. Dickerson that cost-sharing is not likely to decrease costs in the First Steps program. Regarding overutilization, Ms. Arland stressed that two questions must be answered before a strategy is developed on this issue: (1) Does overutilization exist? and (2) If it does exist, is it isolated or pervasive? Above all, any solution implemented in the program must include the needs of children and their families as the top priority.

**Commission Discussion**

Commission member Chris Durcholz commented that as a parent who had gone through the First Steps system, the important role that a service coordinator plays in the program is often not sufficiently acknowledged. He noted that the service coordinator is critical to a family's ability to determine what services a child needs and how to get those services. He suggested that DFC investigate some way to increase the number of service coordination hours that are included in a child's service plan.

**Adjournment**

There being no further business to come before the Commission, Senator Riegsecker adjourned the meeting at approximately 11:50 AM.

(NOTE: Representative Klinker arrived after the conclusion of the meeting but joined the Commission for lunch and was briefed on the content of the meeting by other Commission members and staff.)